A Policymaker's Guide to Long-Term Care in Wisconsin: Public, Private, and Family Perspectives

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In fiscal year 2005, Wisconsin spent nearly $2.2 billion on long-term care; about half for home and community-based services (48%) and half for institutional care (52%). Often forgotten is the unpaid care provided by family and friends, valued at three times that of Medicaid expenditures. These informal caregivers are the only source of care to 78% of the elderly and disabled who need long-term services or support. With an increasing elderly population and less time for families to provide caregiving, policymakers are increasingly searching for ways to reform long-term care such as creating public/private partnerships, improving access to home and community-based care, promoting long-term care insurance, and strengthening asset transfer and estate recovery policies. Policymakers are also finding ways to support informal family caregivers through respite services, support programs, and expansion of family and medical leave.

Long-term care has been called the "sleeping giant" of family policy. As Medicaid has quietly become the nation's largest payer of long-term care services, state policymakers in particular have become increasingly interested in workable reform strategies. This chapter overviews why there is so much interest in long-term care, defines long-term care and differentiates it from acute care, and explains how much citizens, families, the private sector, and Wisconsin's government invest in long-term care. The report concludes by examining what public and private actions are being taken to address this important issue, identifying steps that states are taking to promote family involvement in long-term care, and proposing criteria that policymakers could use to assess how family friendly long-term care legislation is.

Why are Wisconsin Citizens and Policymakers Interested in Long-Term Care?

The number of elderly in Wisconsin is growing. Long-term care policy involves two major populations: (a) people with mental and physical disabilities and (b) the aged. Long-term care needs are increasing because of technologies that keep people alive longer and the aging of the baby boomers. Of all the people in human history who have ever lived past the age of 65, half are alive today.[1]

The number of elderly in Wisconsin grew by over 51,000 between 1990 and 2000, yet their percent of the population remained about the same (see Figure 1).[2,3] In contrast, predictions about the next 25 years show a steady increase in the proportion of residents who are over 65. By 2020, the number of elderly is expected to grow to 1.02 million.[4] By 2030, the number is expected to grow to 1.34 million, an estimated 90.2% increase from 2000.[5] As Figure 1 shows, Wisconsin has a slightly higher percent of elderly compared to the nation as a whole.[6,7]

Figure 1: Number and Percent of Elderly (65 years and older) 1990 to 2030 (estimated)

Year	Number of Elderly in Wisconsin	Elderly as Percent of Wisconsin Population	Percent of Americans who are Elderly
1990	651,221	13.3%	12.6%
2000	702,553	13.1%	12.4%
2020 (est.)	1,022,359	16.7%	16.3%
2030 (est.)	1,336,384	20.8%	19.6%

In 2002, Wisconsin ranked 8th in the nation for percent of people age 85 or older.[8] The oldest old, those 85 years and older, is the fastest growing age group in Wisconsin and will continue to be until 2010. After 2010 the number will increase more slowly, but it is expected that the oldest old will again comprise the fastest growing age group in 2025 once the baby boomers enter their ranks.[9]

Many elderly will need long-term care services. While the majority of elderly do not need long-term care services, the likelihood that they will need services increases with age. In 1999, 15.9% of Americans aged 65 and over received long-term care services of some kind.[10] Of those aged 65 to 69, only 5.7% used long-term care services during the year, compared to 39.8% in the 85-89 age group and 72.1% of those 95 and over.

Long-term care is costly. Whether provided to the growing elderly population or people with disabilities, long-term care is a priority for states because Medicaid accounts for nearly half (47%) of the nation's spending on long-term care services.[11] Estimates show that, in 2004, Medicaid paid one third of all long-term care spending on the elderly and 30% of their nursing home costs.[12] For people under 65 with disabilities, Medicaid paid an estimated 60% of their long-term care services and supports in 1998.[13]

According to the Kaiser Commission on Medicaid and the Uninsured, Wisconsin spent 41.8% of its Medicaid dollars on long-term care in fiscal year 2003, exceeding the national average of 31.6%.[14] Long-term care is costly for individuals and families, too. Seniors who do not qualify for Medicaid pay an average of $70,000 per year for nursing home stays.[15] In 2003, Wisconsin ranked 11th highest in the nation for percent of elderly 65 and over who were in a nursing home—4.9%.[16]

Family caregivers are less available due to competing demands on their time. Most long-term care services are provided in the community, often by family members. Nationally, 75% of people 65 or over who have long-term care needs receive services in the community. The remaining 25% receive care in a nursing home.[17] The vast majority of disabled adults age 18 or over living in the community—about 80%—receive unpaid assistance from family, friends and neighbors.

The ratio of available caregivers to those needing care is expected to decline by almost two thirds by the year 2050 for many reasons. On average, families are smaller, more apt to have two wage earners, and less likely to live close to relatives. As parents have children later in life and find adult children returning to the nest, they are more likely to be juggling responsibilities for childrearing and elder care.[18] The more problems caregivers report, the greater the chances that family members they are providing care for will be institutionalized.[19] In one study, 50% of elderly people with long-term care needs who lacked a family caregiver lived in a nursing home, compared to 7% who had family caregivers.[20]

What is Long-Term Care?

Long-term care includes a broad range of services needed by people with chronic illness or disabling conditions over a long period of time. Long-term care needs are highly correlated with medical conditions such as arthritis, paraplegia, dementia, or chronic mental illness. These services focus on providing assistance with daily activities to minimize, rehabilitate, or compensate for the loss of independence. These services include assistance with a) activities of daily living such as bathing, dressing, and eating and/or b) instrumental activities of daily living such as household chores, meal preparation, cleaning, shopping, money management, and transportation.

One reason that long-term care is such a perplexing policy issue is the range in the type of care that is provided, who provides it, and where it is provided. In regard to the type of care, most long-term care is low-tech, but it may also include high-tech medical interventions such as intravenous drug therapy, ventilator assistance, and wound care. In regard to the caregiver, long-term care may be provided by unpaid family members or friends (informal caregivers) or by specially trained paid professionals and paraprofessionals (formal caregivers).

In regard to where care is provided, long-term care occurs in a range of settings. The most restrictive end of the continuum is nursing home or facility care. Home and community-based care is a catchall for a wide variety of noninstitutional options. Residential care services, such as assisted living facilities and adult foster homes, fall into this category, although there are features of institutional care in these settings. Other settings more clearly classified as home and community-based care include adult day care and care in one's own home. In the home, care is further differentiated between home health care, which includes some level of skilled nursing, and home care, which includes personal care services and homemaking chores.

In What Ways Does Long-Term Care Differ from Acute Care?

One of the most difficult aspects of designing long-term care policy is its inherent differences from the more familiar acute care. Long-term care involves a loss of functional capacity over a period of years; in contrast, acute care is more often a short episodic need for health care. Long-term care requires a series of decisions about the family and institutional supports needed to meet a specific loss of functioning, which is typically followed by another set of decisions as other functions decline. To the contrary, acute care is more apt to require one set of decisions to meet a more well-defined health care need. Long-term care often requires planning for some level of family support, but also identifying and integrating physician, hospital, and sometimes facility care. Acute care often is limited to selecting an excellent physician or hospital.

The dilemma that policymakers face is designing a system without knowing what functions will decline, how long these services will be needed, which medical advances might be developed, and what family supports will be available for the various individuals who will use the long-term care system. Physicians, consumer/patients, family members, and other caregivers are unable to predict whether a patient's particular acute care episode, especially episodes for conditions with lengthy recovery periods, will evolve into a long-term care need. How much functioning will a particular person recovering from a stroke in an acute care setting or receiving rehabilitation in a post-acute setting regain over the course of the treatment? If recovery is faster and more complete, the episode would be considered acute. If recovery is incomplete, the episode would transition to one in which the consumer/patient needs long-term care.[21]

Recently there have been shifts in thinking about long-term care. For example, the disability community is proposing a shift in terms from long-term care to long-term services and supports that allow people to remain in the community. Also instead of talking about quality of care, some people are talking about quality of life at the end of life.[22]

How Much does the State of Wisconsin Spend on Long-Term Care?

Wisconsin Medicaid dollars pay for long-term care services provided in institutions such as nursing homes, State Centers for the Developmentally Disabled, and Veterans Homes, and in home and community-based settings through programs such as the Community Integration Program (CIP), Family Care, the Partnership Program and the Community Options Program (COP). In 2004-2005, the state Medicaid program spent nearly $2.2 billion on long-term care services; 48.2% on home and community-based care and 51.8% on institutional care (see Figure 2). The service expenditures presented on the following page do not reflect acute care services that elderly and disabled Medicaid recipients receive, such as hospital care, physician services, and prescription drugs. The Medicaid costs associated with acute care services are reflected elsewhere in the Medicaid budget.

Figure 2. Wisconsin Medical Assistance (MA) Expenditures for Long-Term Care Services SFY 2004-2005

	Expenditures	Percent of Grand Total
Community-Based Services		
MA Home and Community-Based Waiver Programs (except COP and COP-W programs)	394,882,422	18.1%
Community Options Program (COP) and Community Options Waiver Program (COP-W)	149,533,736	6.8%
Family Care Capitation Payments	171,047,691	7.8%
Independent Care Program	47,445,872	2.2%
PACE and Partnership Programs	88,786,681	4.1%
MA Card Services for Home Care	200,612,650	9.2%
Total – Community-Based Services	**1,052,309,052**	**48.2%**
Institutional Care		
Nursing Homes (other than state facilities)	971,022,000	44.5%
State Veterans Home at King	45,162,000	2.1%
State Centers for the Developmentally Disabled	114,587,000	5.2%
Total – Institutional Care	**1,130,771,000**	**51.8%**
Grand Total	**2,183,080,052**	**100.0%**

Source: Wisconsin Legislative Fiscal Bureau (December 2005), based on information from the Wisconsin Department of Health and Family Services.

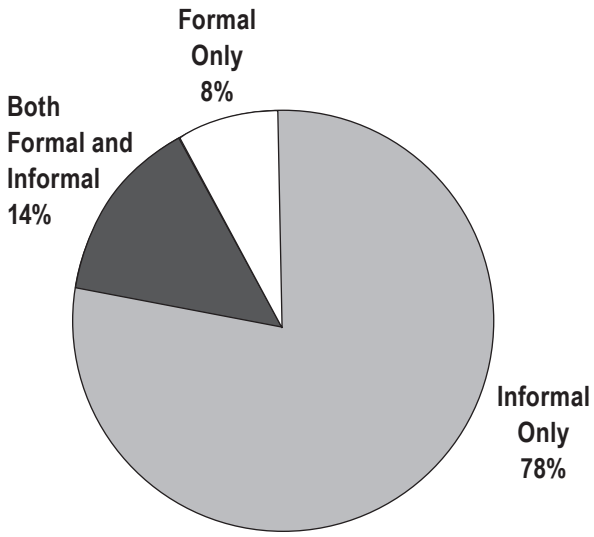
How Much do Family, Friends, and the Private Sector Spend on Long-Term Care?

Both the recipients of long-term care services and their families pay for a significant portion of long-term care services. Whereas Medicaid was the largest payer (40%) of total long-term care expenditures in 2003, out-of-pocket spending was the second highest payer category at 25%.[23] Of nursing home expenditures, out of pocket payments (28%) were again second only to Medicaid (46%).

Perhaps more importantly, the vast majority of long-term care for the elderly and disabled is provided free by informal caregivers. An estimated 44.4 million family members and friends provide care to someone 18 or over.[24] Informal caregivers help with activities such as writing checks, cleaning, buying groceries, attending medical appointments, and administering medications. Not surprisingly, the majority of informal caregivers are family members, with a parent (25%), other relative (21%), child (16%), or spouse (15%) providing the care.[25]

The value of this care does not show up in state or federal budget ledgers. The economic value of informal caregiving in 2002 was estimated to be $256 billion, or three times the $82 billion spent by Medicaid.[26] This value may be a result of the heavy reliance on informal caregivers by adults who receive long-term care services at home. The majority of adults (78%) receive only informal care from family or friends (see Figure 3).[27] A much lower percent (8%) receives only formal care.

Figure 3. Type of Care Received by Adults at Home 1994-1995



Source: Health Policy Institute, Georgetown University. Analysis of data from the 1994 and 1995 National Health Interview Surveys on Disability, Phase II.

These national statistics mirror what is happening in Wisconsin. According to a 2001-2002 survey conducted by the Wisconsin Department of Health and Human Services, citizens 65 and over rely extensively on family members for care.[28] Of the seniors living alone, 80% said someone checks in on them regularly. Children checked in most frequently (53%), followed by neighbors (24%) and friends (15%). Caregiving *by* the elderly does not stop at old age either. Almost a third (31%) of the elderly respondents said they have at least one kind of caregiver responsibility, including caring for a child with a disability, spouse, or grandchild.

Caregiving can take a heavy emotional and physical toll, with an estimated financial impact of $12,500 yearly per caregiver to cover expenses such as groceries, medications, and home modifications.[29] Over 6 in 10 (62%) of caregivers report that they have to make workplace accommodations to meet caregiving demands. This lost productivity is estimated to cost employers between $11 and $29 billion per year.[30]

What are Citizens Doing to Plan for Future Long-Term Care Expenses?

In early 2005, the Kaiser Family Foundation conducted a national poll on the public's views on long-term care and nursing homes.[31] Over one-fourth of Americans (28%) said they are "very" worried that they won't be able to pay for nursing home and home care services. Over a quarter (26%) say they have given "a lot" of thought to how they will pay for long-term care.

In the Kaiser survey, three in ten (30%) said they would pay for nursing home care with insurance for themselves or family members. Fewer people said they would use personal savings (16%) or government programs such as Medicare or Medicaid (13%). Contrary to the poll results, however, private insurance is estimated to pay only a small share of nursing home expenses (8%), whereas Medicaid finances almost half (46%) of nursing home care.

About one in five (21%) report having a long-term care policy. The 79% without insurance said that the cost was too prohibitive (59%) or they had not thought about insurance (32%). A federal tax credit appears to be an incentive to purchase insurance for some consumers. About half (48%) said they would be more likely to buy a policy if there was a credit; the same number (48%) said they would not.

The vast majority of the survey respondents (84%) have had some experience with nursing homes as a patient, family member of a patient, or visitor. About half (46%) said a family member or close friend has been in a nursing home in the past 3 years. Only about one in ten (12%) said they would choose to receive care in a nursing home if they required full-time care. More (39%) would choose to receive care in a hospital.

What Could States Do to Reform Long-Term Care?

Last year, the National Governors Association (NGA) released a report on Medicaid and health care reform.[32] Below are selected reform strategies that NGA says states could implement:

- Prevent inappropriate asset transfers. NGA recommends increasing the look-back period from three years to five years (or longer), beginning the penalty period at the time of application, and preventing the sheltering of annuities, trusts, and promissory notes.
- Reverse mortgages. Home equity could be considered a countable asset in offsetting long-term care expenditures. Reverse mortgages and other similar approaches require some form of family contribution to long-term care costs.
- Tax credits and deductions for long-term care insurance. Currently about 28 states, including Wisconsin, provide deductions or tax credits for long-term care insurance.
- Long-term care partnerships. Although their approaches differ, California, Connecticut, Indiana, and New York offer insurance policies which allow individuals to purchase private insurance and still protect some of their assets. Federal law currently prohibits expansion of these partnerships to other states, but 17 states have passed enabling legislation in the event that the prohibition is repealed. Wisconsin has legislation on the books that requires the Department of Health and Family Services to seek federal approval and financing for a project that would allow Wisconsin Medicaid recipients to keep more of their assets if they purchase long-term care insurance. [See Sections 49.45(31) and 146.91, Wis. Stats.]
- Improving access to home and community-based care. Such care is believed to produce better health outcomes and results in greater efficiencies.
- Improving chronic care management. The chronically ill are a small population in Medicaid that uses a large share of resources.
- Assisting and supporting in-home workers. More than 20 states have passed legislation to increase direct-care workers' wages with state or Medicaid funds.

What are States Doing to Promote Family Involvement in Long-Term Care?

Over a decade ago, the Consortium of Family Organizations recommended reframing the terms of the long-term care to the individuals, mostly family members, who provide the bulk of long-term care. As mentioned earlier, the elderly without family caregivers are over 7 times more likely to be in a nursing home than those with a family network. Given data like these, the key to controlling costs and improving the quality of the care is focusing on the central policy question—how can we support, supplement, and strengthen family caregiving. Responding to this central policy question has become more complicated given recent changes in family life.

Last year the National Governors Association summarized the options states have used to support family caregivers.[33] The six strategies are briefly summarized below.

- Using state and federal funds to support respite services. States are providing the service that family caregivers say they most need—respite and day care to provide time away from the stresses of caregiving.[34] State program directors believe that expanding caregiver support programs can reduce

the strain on Medicaid and other state-funded home and community-based options. Oklahoma, Oregon, and Nebraska are integrating federal, state and local dollars to coordinate respite care for caregivers, regardless of the age of the care recipient. Nebraska provides a subsidy of $125 per eligible family client per month, which can be banked for up to three months.

- Using state revenue to support family caregivers. California and Pennsylvania use general revenues to provide comprehensive caregiver programs. Wisconsin's Family Caregiver Support Program varies across counties, but each county's program encompasses five components: information about services, assistance in accessing services, individual counseling and training to caregivers, respite care, and supplemental services.
- Maximizing choice for consumers and caregivers. Arkansas, Florida, and New Jersey are piloting a self-directed care model known as *Cash and Counseling.* Medicaid long-term care recipients are paid cash allowances to hire workers (excluding spouses and relatives) and purchase goods and services that meet their needs. North Dakota, which has a shortage of health care workers, provides eligible family members a monthly payment to care for a live-in relative, who would otherwise qualify for nursing home admission.
- Improving the tax treatment of caregiver expenses. At least 26 states offer dependent care tax credits, which reduce the amount of income taxes a family owes for dependent care.
- Expanding family and medical leave. The federal Family and Medical Leave Act guarantees employees of businesses with at least 50 employees 12 weeks of unpaid leave each year to care for a newborn, newly adopted child, or seriously ill family member. States have expanded their laws in several ways; if Wisconsin has such a law, it is included below:
    - Allowing public and private-sector employees to use their leave to care for an inlaw or grandparent (Washington); Wisconsin law allows taking family leave to care for an inlaw, but not a grandparent (unless the grandparent is raising the child)
    - Expanding leave provisions to workplaces with fewer than 50 employees (Oregon and Vermont)
    - Extending the 12 week leave period (California, Connecticut, Louisiana, Oregon, Rhode Island, and Tennessee)
    - Allowing family medical leave for conditions not covered by the federal law (Maine, Massachusetts, Vermont, and Wisconsin); federal law excludes serious health conditions of less than three days, whereas Wisconsin law will cover serious health and disabling conditions of a shorter duration (e.g., a person who dies after a two-day hospitalization); neither federal or state law covers leave for a caregiver whose child or elder is too sick to go to child or day care, but is not seriously ill
    - Allowing leave with some wage replacement through disability insurance or sick leave (California, Hawaii, Minnesota, Oklahoma, Washington, and Wisconsin)
    - Offering paid family leave through the state's disability insurance program (California)
    - Promoting public/private partnerships and public awareness. Some states are educating employers about the effects of caregiving on their employees' productivity, and other states are raising general awareness of the needs of family caregivers through statewide outreach and marketing efforts.

What Criteria can Policymakers Use to Assess how Family-Friendly Long-Term Care Legislation Is?

The Wisconsin Family Impact Seminars encourage policymakers to acknowledge and take into account the crucial role that family caregivers play in providing long-term care. Family-friendly polices would assist families in providing care for the disabled and the elderly without requiring total sacrifice of other personal, family, or occupational pursuits. At the same time, such policies would not absolve individuals of any responsibility to care for and assist family members who have long-term care needs. Legislators can assess laws and legislation for its impact on family well-being by raising and responding to the following family impact questions.

- Does the policy support and supplement family functioning and provide substitute services only as a last resort?
- Does the policy encourage and reinforce marital, parental, and family commitment and stability?
- Does the policy recognize the interdependence of family relationships, the strength and persistence of family ties and obligations, and the wealth of resources that families can mobilize to help their members?
- Does the policy encourage individuals and their close family members to collaborate as partners with programs or professionals in the delivery of services to an individual?
- Does the policy take into account the varying effects on different types of families?
- Does the policy support those in greatest economic and social need, as well as those determined to be most vulnerable to breakdown?

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